

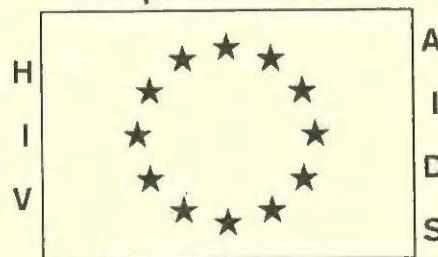
Children, Families and HIV: The Global Picture

*A report on the Tenth International Conference on AIDS/
International Conference on STD
held in Yokohama, Japan,
7-12 August 1994*



Neil Orr

European Forum on



Children and Families

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Project aims:

- Promote the needs and raise awareness of HIV affected children and families.
- Develop a multidisciplinary Forum in Europe.
- Promote collaboration and coordination between Forum members.
- Identify unmet needs through cooperative studies and action.
- Provide information exchange and publish a European newsletter.
- Disseminate the results of good practice models.
- Promote child and family-centred services.
- Promote the legal and social rights of children.
- Promote the views of children.
- Promote HIV prevention programmes which address discrimination.

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PREFACE:

**THE EUROPEAN FORUM ON HIV/AIDS,
CHILDREN AND FAMILIES**

The European Forum on HIV/AIDS, Children and Families was launched in January 1994 with the aim of promoting the needs and raising awareness of HIV affected children and families across Europe. The Forum was established as a result of the 'Symposium on the needs of children and families affected by HIV - a European perspective' held in Torgiano, Italy, in 1993.* The Symposium brought together 35 specialists from eight countries and a diversity of backgrounds to address such areas as health and social services, substitute care and schooling.

The Symposium identified a number of key principles for the development of policies, services and practice. It was agreed that rather than an exclusively medical approach focusing on the individual child infected with HIV, a more holistic family-based approach is required which is also able to respond to the wider social and psychological needs of the family as a whole. This approach should also be child-centred, taking into account the needs of children and acknowledging their rights to express their views. The Symposium emphasised the need for greater co-ordination between health, education and social services to provide care that is flexible, accessible and responsive to changing family needs.

Among the recommendations of the Symposium was the setting up of a European Forum based upon these principles. The Forum is sponsored by the National Children's Bureau and the Institute of Child Health, with participating centres in France, Italy, Portugal, Spain, and the UK. The activities of the Forum to date have included publishing a newsletter in five languages, and developing proposals for a number of inter-country projects.

The Forum has received funding from the European Commission, who kindly made it possible for a representative to attend the Tenth International Conference on AIDS in Yokohama. In accordance with our aim of disseminating the latest available information on children, families and HIV, the Forum is pleased to present the following report of the Yokohama Conference.

Naomi Honigsbaum (Co-ordinator)

* The Symposium report 'Children and families affected by HIV in Europe - the way forward' by Naomi Honigsbaum has been published by the National Children's Bureau, price £5.00 (£3.50 for Bureau members), plus postage, packing and order processing of £3 for orders up to £28, £6 for orders over £28.

INTRODUCTION

The Tenth International Conference on AIDS, held for the first time in Asia, brought together 10,000 participants from 140 countries. Researchers, clinicians, policy makers, community workers, activists and others gathered under the slogan 'The global challenge of AIDS: together for the future' for four days of information sharing and discussion.

As well as the main plenary sessions, 600 oral reports and 2800 poster presentations were divided into four tracks: basic science; clinical science and care; epidemiology and prevention; and impact, societal response and education. This report does not aim to cover all the proceedings of the conference, but attempts to summarise those parts which focused on the impact of HIV on children and families, and the global response to this impact.

In the course of the conference, the global picture of the epidemic became clearer. However, it should be borne in mind that this report does not provide a comprehensive overview of the state of knowledge about children, families and HIV. Some important studies in progress were not presented at Yokohama, and some of these might come to different conclusions to those that were presented. In addition the significance of the studies presented is open to discussion; the interpretation here is the sole responsibility of the author.

EPIDEMIOLOGY

In his opening address, Michael Merson of the World Health Organisation warned against complacency in the fight against AIDS. Last year, more people were infected with HIV, and more died from AIDS than in any previous year. The WHO estimates that 6000 people are being infected every day and that at least 17 million people have now been infected worldwide, including a million children born to mothers with HIV.¹

Sub-Saharan Africa has borne the brunt of the epidemic, accounting for 62% of infections. 60% of new infections in this part of the world are among people aged 15 to 24. The last year has seen significant increases in the rate of infection in southern and western parts of Africa previously relatively unscathed. Unlike elsewhere in the world, more women than men are infected in sub-Saharan Africa, and this has obvious implications for the epidemic in children.

Data were presented on HIV prevalence in pregnant women, and paediatric AIDS cases in various parts of the world:

HIV prevalence in pregnant women

Country/area	Year	Rate per 1000
Abidjan, Cote d'Ivoire ²	1992	100 - 150
Chiang Rai, northern Thailand ²	1993	80
Hlabisa district, South Africa ³	1993	42
Bahamas ²	1990-91	30
South Africa ²	1992	24
Thailand ²	1993	15
Bombay, India ⁴	1993	12
Santo Domingo ²	1990-91	> 10
Sao Paulo, Brazil ²	1990-91	> 10
Dominican Republic ²	1990-91	> 10
Paris, France ⁵	1993	6
London, England ⁶	1993	2.6
United States ²	1991-92	1.7
Amsterdam, Netherlands ⁵	1990	1.02
Sweden ⁵	1991	.19
Norway ⁵	1988-91	.05

Paediatric AIDS cases

Country/area	Date	Number of cases
Europe ⁷	March 1994	4679
Romania		2547
Spain		564
France		505
Italy		422
UK		142
Germany		96
Russia		90
Belgium		89

(all other European countries < 50 cases each)

USA ⁸	March 1994	5438
Brazil ⁷	May 1994	1614
Sao Paulo state, Brazil ⁹		875
Chile ¹⁰	January 1994	12

MOTHER-TO-CHILD TRANSMISSION

Previous estimates of the rates of mother-to-child transmission of HIV have ranged from 16% in the European Collaborative Study to 43% in a Kenyan study. Data from several studies were presented in Yokohama; in Uganda 24.4% of 390 infants born to mothers with HIV were infected,¹¹ while in Thailand the transmission rate in a cohort of 105 children was 25.7%.¹²

Transmission can occur through the placenta, during birth, and via breastfeeding. Stephane Blanche presented data from the French prospective study suggesting that late transmission around the time of birth accounts for most mother-to-child transmission. Fetal infection is rare before 20 weeks, and virus was not detected at birth in 65% of children subsequently found to be infected with HIV. As a result of an analysis of early diagnostic markers in about 100 infected infants, Blanche and his colleagues hypothesise that 35% of children are infected before birth and 65% during birth.¹³

The mother's clinical status and CD4 cell count seem to affect the likelihood of transmission. In the French study, the vertical transmission rate was 16% in women with CD4 counts of more than 600 compared with 45% in women with less than 200 (however smaller Italian¹⁴ and Spanish¹⁵ studies did not find this correlation). It also appears that the risk of early transmission is higher in women with a higher viral load.

Data from a US study of 132 births suggest that 'prolonged rupture of membranes in HIV-1 infected women delivering vaginally is a risk factor for perinatal transmission of virus. The increased risk is presumably due to the infant's exposure to maternal cervical and vaginal secretion and blood during labor and delivery'.¹⁶

An Italian study has been looking at vertical transmission of hepatitis C virus (HCV) and HIV infection. 17% (9/52) of children born to mothers with hepatitis C were HCV infected, but although all of these children also had mothers with HIV none of them were infected with HIV.¹⁷

SEXUAL TRANSMISSION AND PRIMARY PREVENTION

According to Michael Merson 'up to three quarters of new infections occur in young people under 25. Boys and girls must be given information, skills and support for AIDS prevention before they become sexually active'.¹⁸ At present many young people at risk of sexual transmission of HIV are not being given this information.

HIV education in schools

As Anna Barthes of UNESCO noted, 'The school system has an important role to play in education for the prevention of AIDS among young people'.¹⁹ The dominant cultures in many countries often act as a barrier to effective HIV education in schools, but it should not be assumed that all young people think and act in accordance with these values. In India for instance 'Students desire and seek authentic information on sex and sexuality' but 'though consensus is gradually emerging in favour of sex education, school curricula remain conservative and hesitant to incorporate sensitive issues like the use of condoms'.²⁰ A study from Morocco reported that 'For the majority of parents, the discourse of prevention should be focused on abstinence and religious facts only, but the students want to receive clear and honest information'.²¹ Among 3000 school children aged from 14 to 17 in Tanzania, 90% said that they had had sex, and 95% didn't 'see why religious/cultural norms should prohibit use of condoms'.²² According to a participant from Malaya 'Asian youths, like their

counterparts in the West, are becoming sexually experienced at an earlier age. Yet sex education, particularly about safe sex, is almost non-existent in schools".²³

In some countries, attempts are being made at a national level to develop comprehensive HIV/AIDS education programmes. In Zimbabwe, the Ministry of Education and Culture is supporting an AIDS action programme for schools. It aims to integrate AIDS education into the curriculum for all children from aged nine upwards. Teachers are being trained in facilitating participatory learning, and 'master schools' are being targeted for concentrated training so that they can serve as an example.²⁴ In Italy, although 'sex education in... schools is still not compulsory and is often opposed', the Ministries of Health and Education have supported a training programme for 4000 high school principals in order to facilitate the introduction of AIDS education in schools.²⁵ In January 1994 UNESCO and the WHO held a planning seminar in New Delhi to develop national school curricula on HIV for 12 Asian countries.²⁶

'Socially apart youth'

Ana Filgueiras directs the Hand-in-Hand Network, an NGO working with young people in Rio de Janeiro, Brazil. She called for a greater emphasis on education, prevention and care for 'socially apart youth', those street kids, refugees, abused children, and others who 'are outside the social system and lack access to services and information'. These young people 'are denied full human rights' and are vulnerable to exploitation in the sex trade, violence, 'use of multiple drugs to cope with physical and emotional pain, stress caused by fatigue, fear, a lack of self-esteem, ill-health' and many other problems.²⁷

In designing programmes and services we need to 'provide a safer, supportive, and sustained environment', recognising that these young people 'have needs, desires, and dreams like children in any culture in any part of the world. Like all children they need to be loved and listened to. They need for us to leave behind our preconceived ideas and prejudices about them, and to approach them and their problems on their level as individuals'.

Filgueiras drew particular attention to the needs of young women, who tend to get infected at a younger age than men (60% of all infections in females occur by the age of 20). There is evidence that in some countries older men 'are now seeking out young women for sex in the belief that these girls are less likely to be infected with HIV'. She also referred to gay and lesbian youth who 'in developing or developed countries are pushed out of their homes', facing discrimination and abuse.

Many children are involved in the global sex industry. UNICEF estimate that 15,000 boys, many under 14, are involved in prostitution in Sri Lanka. In Thailand and Cambodia, girls as young as 11 are sold into brothels by family members of kidnappers.²⁸ Within Europe, women as young as 12 or 13 from the Czech Republic and Poland are involved in cross-border prostitution selling sex to German men. A German-based pilot programme of cross-border HIV prevention has been established.²⁹

Young people may be vulnerable in a range of other situations. A US study of runaway/homeless street youth found that crack use predicted high-risk sex and drug injection behaviours.³⁰ Another paper from Sierra Leone drew attention to the high risks of HIV infection for children and young people in times of war.³¹

Prevention programmes for young people using a number of approaches were described in Yokohama including peer education in Jamaica,³² Thailand³³ and India,³⁴ drama in Sierra Leone³⁵ and Burkina Faso,³⁶ and a photo comic in South Africa.³⁷ A Europe-wide campaign aimed at young holiday makers has used leaflets, posters, and television adverts.³⁸

A Puerto Rican study emphasised that young people's social networks appear to influence their risk behaviour. Combining data from interviews with 117 adolescents (aged 12 to 15), the study found that 'youth associate with friends who share similar sexual and drug use behaviors'. For instance, those who reported no drug use 'evidenced a network of friends of almost exclusive non-drug users'.³⁹

An Australian study focused on how adolescents 'may need to progress through a number of stages before developing a firm conception of their sexual self'.⁴⁰ The authors identified five 'sexual styles' (Sexually Idealistic, Unassured, Competent, Adventurous and Driven) and suggest that some of these predicted sexual risk taking.

Sexual abuse

In the US, a small number of cases of children infected with HIV through sexual abuse have been identified. Although this is a rare occurrence 'sexual transmission of HIV occurs in children through sexual abuse and should be considered as a possible means of HIV transmission particularly for older children'.⁴¹ Since August 1993, the paediatric HIV/case report form in the US has included information on possible sexual risk.

Another US study found that 'sexual abuse early in life predicts involvement in high-risk sexual behaviours later in life'.⁴² Out of 2,794 female partners of injecting drug users, childhood and adolescent sexual

abuse were reported in 36.3% and 34.4% respectively. Such sexual abuse correlated with a higher likelihood of trading sex for drugs/money and contracting STDs. A study of women with HIV using a clinic in Philadelphia found that more than half had experienced some form of abuse in their lives.⁴³

A poster from Colombia described a cycle of sexual abuse amongst homeless youth, with teenagers (known as 'largos' or longs) abusing younger children (known as 'chinchies' or bedbugs). As the children grow up 'the abused becomes the abuser'.⁴⁴

BLOOD PRODUCTS

HIV infection via blood products is a continuing source of political controversy around the world. In Japan for instance more than half of the 3389 cases of HIV are accounted for by haemophiliacs infected through blood products (as of June 1994), 60% of whom were infected as children. Haemophiliacs are suing the government and five pharmaceutical companies for continuing to supply infected blood products after the risk of HIV infection became known. Japan did not switch to heat-treated blood products until July 1985, more than two years after the US made this switch. People living with HIV have complained of hospitals refusing to treat them, and of other forms of social discrimination. One plaintiff in the Tokyo law suit testified that his child was forced to leave a nursery school because he was infected with HIV.⁴⁵

Children in Africa and elsewhere with sickle cell anaemia have also been exposed to HIV infection through blood transfusions,⁴⁶ as have children with thalassaemia.

HIV IN CHILDREN

Definitions and diagnosis

The Centers for Disease Control, USA, is introducing a new classification for HIV in children, with the four main categories being N (asymptomatic infection), A (mild symptoms), B (moderate to severe symptoms), and C (corresponding to an AIDS diagnosis).⁴⁷

The definitions of HIV and AIDS used in the US and Europe may be difficult to use in countries without the resources to routinely carry out expensive laboratory tests. On the other hand the World Health Organisation's provisional paediatric AIDS definition has been found inadequate in some settings, lacking sensitivity (in a Brazilian only 21% of children with AIDS were recognised as such by the WHO definition). The Ministry of Health in Brazil has been working with experts to develop its own simplified paediatric AIDS case definition for use where HIV testing is available.⁴⁸

Using a combination of Polymerase Chain Reaction (PCR) tests and culture assay results 'infection status can be efficiently determined by age three months' in HIV-exposed infants.⁴⁹ In a study of blood samples from 491 children with HIV enrolled in the US Women and Infants Transmission Study, 25% of specimens were PCR positive at seven days, and 100% at six months.⁵⁰

Natural history of HIV infection in children

The French prospective study has followed 248 infected children. 20% of these developed AIDS in the first year of life, after which children progressed at the rate of 2-3% a year. There is a bimodal pattern of HIV disease in children, with 15-20% developing rapid immune deficiency and severe encephalopathy, and dying within four years. More than two thirds of those still alive at 60 months have no symptoms however, and 70% of children born with HIV are alive at six years.⁵¹ The long term outcome is still unknown, but at least some children will reach adolescence.

The pattern of disease varies in different parts of the world. In a Ugandan prospective study of 386 children born to HIV infected mothers, 52% of those children known to be infected died within two years of birth. The infant mortality rate among infected children was ten times that among uninfected children.⁵²

Of 419 children followed in a specialist service in Sao Paulo, 81% were vertically infected. Over half of these (52.5%) died in the first year of life. Unlike in Europe, *Pneumocystis carinii* pneumonia (PCP) was infrequent as a cause of death, with septicemia and bacterial pneumonia being the main causes of death.⁵³ In Brazil as in many developing countries in particular, 'Tuberculosis is a highly significant coinfection in HIV infected children'.⁵⁴

Whether children progress early may be linked to the stage of the mother's disease at their birth, and to her viral load. In the French study, where HIV was detected at birth, children were four times as likely to progress early.⁵⁵ This also suggests that children infected earlier in pregnancy develop AIDS quicker, although some children known to have been infected later as a result of blood transfusions have also progressed early. Even perinatally infected twins may have divergent disease courses; in a US case one twin developed AIDS by seven months, while the other had only relatively minor symptoms by 18 months. Viruses isolated from twins differed in their biological properties, and it was suggested that this might 'contribute to the marked differences in the clinical manifestations'.⁵⁶

Although failure to thrive and chronic diarrhoea are

common in children with HIV there is limited data on the causes of these, with standard microbiological techniques failing to identify a significant infectious agent. A study in Baltimore using molecular techniques has detected herpes simplex virus, HIV, cytomegalovirus and *pneumocystis carinii* in tissue and stools from children with these complaints. Researchers suggest that these pathogens may play a role in causing failure to thrive and chronic diarrhoea, a finding with potential therapeutic implications.⁵⁷

Nutrition may also affect disease progression. In a Romanian study HIV-infected children living in orphanages developed symptomatic infection quicker than those living with their families, with the authors suggesting that this was related to their nutritional status. In 1990, 90% of children from orphanages had protein energy malnutrition compared with 25% in the group living with families.⁵⁸

Oral health

In a US study of 63 HIV-infected children, the prevalence of oropharyngeal candidiasis (oral thrush) was 70% by the age of two. Noting that 'Orofacial manifestations are commonly associated with pediatric HIV infection', the authors conclude that 'Primary care of these patients should include a careful oral examination at regular intervals and early interventions'.⁵⁹

In Brazil a preliminary study of 90 children with AIDS found that the most common oral manifestations were lymphadenopathy (34.6%), candidiasis (30%), and parotid gland enlargement (30%). Only 38.5% of children had received oral hygiene guidance. Dentists in Brazil are working to create a case definition of AIDS based on oral manifestations that can be used by dentists in developing countries.⁶⁰

Neurological aspects

In the French study most children who survive the first few years of life perform as well as other children at school, and come in the normal range in psychometric tests. 66% of children had normal school results, and 16% were borderline.⁶¹ Of the remainder who fared badly, the study found that this was associated with low CD4 counts rather than social factors or even clinical symptoms, suggesting that the virus itself may affect performance possibly through its effect on the brain.

Uninfected children

Growth failure and increased mortality are common among children with HIV. A study from Haiti involving 191 infants born to infected mothers also

found that 'uninfected children born to HIV-1 seropositive women exhibit poorer growth and survival than infants born to seronegative mothers'.⁶² Research is continuing into the reasons for this. In a Ugandan cohort however there was no significant difference in mortality between uninfected children of infected mothers, and children born to seronegative mothers.⁶³

Normand Lapointe and colleagues in Montreal have found that some non-infected children born to HIV infected mothers seem 'to sustain unexplained immunological injury'. 10% of 70 non-infected children had sustained or recurrent immunosuppression over time without detectable HIV infection.⁶⁴

TRIALS AND TREATMENT

Zidovudine (AZT) and mother-to-child transmission

James Balsey of the US National Institute of Health presented data from the highly-publicised ACTG 076 trial on the use of zidovudine (AZT) to reduce perinatal transmission of HIV.⁶⁵ Preliminary results of this joint US/French study suggest that AZT may reduce by up to two thirds the risk of transmitting HIV from infected pregnant women to their babies.

Women in the trial received either AZT or a placebo during pregnancy and labour, and for six weeks after birth infants received the same treatment as their mothers (that is AZT or placebo). By 20 December 1993, 421 babies had been born of whom 364 had been accurately tested for HIV. Of these 364, 53 had HIV, 13 of them born to mothers receiving AZT, and 40 to mothers on placebo. The transmission rate was 8.3% when both mothers and babies received AZT, compared with 25.5% amongst those receiving a placebo. Following an interim review of the trial by an independent Data and Safety Monitoring Board, enrolment to ACTG 076 was stopped, and all pregnant women still on the trial were offered AZT (including those who would have been given a placebo).

While positive about the possible benefits demonstrated by the trial, Balsey urged caution in interpreting these results:

- the long term adverse effects of AZT administered during pregnancy are unknown;
- women enrolled in the trial had CD4 counts of more than 200 and had not taken AZT previously. The drug might not have the same effect with other women with HIV who do not meet these criteria;
- AZT was administered before, during and after birth. It is not known which of these interventions was crucial;
- women who use AZT during pregnancy may

develop AZT-resistant strains of the virus, which may lessen the drug's therapeutic benefit for them at a later date.

Follow up of women and children is continuing. US recommendations on AZT and pregnancy have now been issued which stress that 'health-caregivers and institutions should provide culturally, linguistically and educationally appropriate information and counselling to the HIV-infected woman so that she can make informed decisions'.⁶⁶

In her speech at the closing ceremony, Noerine Kaleeba from Uganda said that many young women there were asking why, if AZT was effective in reducing mother-to-child transmission, did they not have access to it?

There have been renewed calls from some quarters in the US for mandatory HIV testing of pregnant women in the light of the trial. Dr Balsey stated that he personally opposed this proposal, and this subject was further discussed in a presentation by Elizabeth Cooper.⁶⁷ While acknowledging the benefits of early identification of infected women and children, she argued that this is best facilitated by universal counselling with voluntary testing. Mandatory testing may reduce access to health services, as some women may avoid perinatal care altogether. This may be particularly true of some immigrant women in the US who may fear deportation if their HIV status is revealed. In the light of the uncertainty about the effects of AZT in pregnancy, women who do test positive may in any case choose not to take the drug. Cooper argued that mandatory testing would be discriminatory, and may open the way for further violations of human rights such as the criminal prosecution of women for transmitting HIV to children (there is a precedent for this in the US with women being prosecuted for drug use during pregnancy).

Michael Merson also argued against mandatory screening on principle, noting that it is the less powerful who get tested, patients rather than doctors, sex workers rather than their clients.

Other trials:

The PENTA 1 (Paediatric European Network for Treatment of AIDS) trial, comparing early with deferred treatment of AZT in children with vertically acquired HIV, is in progress. As of June 1994, 147 of the planned 400 children have been recruited to the trial from 32 centres in nine countries. Recruitment is being extended outside Europe to Canada and Brazil. The PENTA 3 trial comparing toxicity and tolerability of AZT alone, with AZT and ddC, has a planned intake of 100 children and is starting this year.⁶⁸

Michael Brady presented results of the US trial ACTG 128,⁶⁹ comparing standard and low doses of AZT in children. Adult trials have previously demonstrated that a lower dose is as effective as the higher dose. In this trial, 426 mild to moderately symptomatic children from 57 centres were randomly assigned to receive either the standard dose (180 mg/m²) or low dose (90 mg/m²) orally every six hours. The trial was completed in February 1994. After a median three years treatment there were no statistically significant differences between the two groups in terms of toxicity, survival, disease progression, CD4 counts or neurological assessment. Dr Brady therefore recommended that the lower dose should become the new standard dose.

Data were also presented from US trial ACTG 153, which aims to determine the maximum-tolerated dose and the toxicity/tolerance profile of escalating doses of alpha-interferon (INF-A) in HIV infected children.⁷⁰ Alpha interferon is a natural protein produced by the human body in response to infection which can be manufactured using genetic engineering techniques. It has been hypothesised that AZT and alpha interferon together may be more effective than AZT alone, although trials in adults have been inconclusive. In ACTG 153, 45 children received different doses of INF-A ranging from 2 to 14 mu/m² three times a week in combination with AZT. Side effects included flu-like symptoms, anaemia and weight loss. 50% of those taking the highest dose experienced severe adverse effects, and the maximum tolerated dose has therefore been defined as 10 mu/m². The authors conclude that 'The majority of children enrolled in this study were able to tolerate as many as 24 weeks of continuous alpha-interferon therapy' with AZT.

Trials involving the use of potentially toxic substances in children clearly pose important ethical questions. In the case of the above trial, Dr Diaz stated that as well as parents having to give informed consent, children over five years of age were given separate explanations about the purpose of the trial and had to give their own consent.

There was some discussion of the possibilities of gene therapy, which aims 'to repopulate the immune system with genetically altered cells that resist infection'.⁷¹ Dr Wong-Staal and her colleagues are hoping to start US trials in new born children in the near future, involving inserting a gene into the stem cells which help produce new blood cells. This gene would enable cells to produce an enzyme (hairpin ribozyme) which has been shown to act against HIV in laboratory tests. Researchers at St Jude Children's Research Hospital in Memphis have been exploring another approach focusing on the role of the *nef* gene, which is present in HIV, in disease progression.⁷²

Prophylaxis

In the USA and elsewhere, *pneumocystis carinii* pneumonia (PCP) is a major cause of death in children with HIV. Although PCP can be largely prevented by prophylaxis, there has been no decline in PCP cases in infants since prophylaxis guidelines were published in 1991. A review of 223 cases of PCP found that 76% had not received prophylaxis; many of these cases 'can be attributed to lack of timely evaluation for HIV' demonstrating that 'HIV screening and PCP prophylaxis strategies must be improved to maximally prevent PCP in infants'.⁷³

SOCIAL AND PSYCHOLOGICAL ASPECTS

'AIDS orphans' and substitute care

Most of the papers on the social impact of AIDS on children and families focused on 'AIDS orphans' a term used somewhat loosely to refer in some cases to children whose parents have both died, and in some cases to children whose mothers have died.

The WHO estimates that over five million children under ten years of age will be orphaned by the end of the 1990s as a result of their mothers dying from AIDS. Estimates of the numbers of 'AIDS orphans' in Uganda by the year 2000 range from 410,000 to 880,000, and in Zambia from 320,000 to 990,000.⁷⁴

There were some discussion of how best to meet the needs of such children. Eric Chevallier presented the Lusaka declaration on 'Support to children and families affected by HIV/AIDS' agreed by NGOs from eight African countries at a workshop in February 1994.⁷⁵ One principle agreed at this workshop was that orphanages, heavily dependent on outside funding, are generally inappropriate for caring for children and that alternative solutions need be found. Mazuwa Banda from Zambia agreed, arguing that such institutions detach children from the wider community.⁷⁶ However residential care might have a role to play in some circumstances, such as for sick children.

Orphans in Africa have traditionally been cared for through extended family/kinship systems. However the extended family system has come under increasing stress due to social trends such as urbanisation, and due to the impact of AIDS. In some cases AIDS has 'claimed the lives of many adults, leaving behind large numbers of children to be cared for by the very few adults who in some cases are only grand parents'.⁷⁷ A study in Namibia found that 'Contrary to some popular wisdom the extended family in this part of sub-Saharan Africa is not extensively involved in the support and care and someone with HIV', with 54% of a sample of people with HIV not disclosing their diagnosis to anyone including family members.⁷⁸

A study from Kenya looked in detail at what happened to 98 children who had suffered the death of a parent. In all 39 cases where the father died, the child continued to be looked after by the mother. In 32 cases where the mother died, 13 children were cared for by the surviving father, 13 by the maternal family, and six by the paternal family. Where both parents died, 17 were cared for by the paternal extended family, four by the maternal family, and six in institutions. Some children have been rejected by extended families, by schools, and by the wider community.⁷⁹

As well as providing support to the extended family, other non-institutional approaches have included providing material and emotional support to older siblings to help them care for younger siblings, skills training to help children make a living, and fostering and adoption. However 'Current strategies fall far short of the great need that exists'. Successful strategies should 'start off with an existing situation and then go about modifying it',⁸⁰ involving local communities as principal actors rather than agents from outside.

This problem is of course not confined to Africa. In Brazil for instance a large number of children are institutionalised having been abandoned soon after birth in addition to those whose parents have died.⁸¹ In the French prospective study, of those children separated from their mothers, 43% were cared for in the wider family, with 57% being placed by institutions. Younger children were more likely to be in the latter group, with none of the children separated from their mothers after the age of four being cared for outside of the family.⁸²

Eric Chevallier stated that the issue is broader than one of 'AIDS orphans' since the impact of AIDS on children begins long before the death of a parent. As Banda remarked 'The total effect of HIV/AIDS on children is... very severe. It attacks their bodies, their personality, their potentials and their future'. Many aspects of the impact on children were however inadequately addressed at the conference.

Schooling issues

Although there were many papers on HIV education in schools, there was very little on the implications for schooling of children already living with HIV. In some parts of the world families are unable to meet schooling expenses and so children drop-out of school. Other children have to drop out to look after parents and siblings. Those children who continue to attend school 'sometimes find themselves unable to cope... due to underlying emotional and psychological problems'.⁸³

The attitudes of school staff and students can also act as barriers to education for children with HIV. Out of a sample of 870 teachers in Hong Kong, only 41% believed that children with HIV should be kept in normal classes.⁸⁴ A better knowledge of AIDS was associated with a more positive attitude to normal schooling, demonstrating the importance of HIV education for teachers as well as students.

Sheldon Shaeffer of UNICEF observed that 'in many countries of the world HIV and AIDS are beginning to have an impact on education as a system... with evident declines in educational demand, supply, and quality'.⁸⁵ For instance in some areas, schools may become unviable due to declining numbers of children attending. Responding to this involves convincing those responsible for education that AIDS is not just a health problem, and that their planning should take into account the impact of AIDS.

Migrant families

There was little recognition at Yokohama of the specific needs of children and families in particular communities. In Europe for instance, many families living with HIV are migrants from Africa and elsewhere. Among the problems facing such families is that relatives may be living thousands of miles apart, as was shown in one study from four hospitals in South London, England, of 86 HIV infected patients from Africa (69% of them from Uganda). 42 of these are parents with a total of 54 children living in the UK, and another 35 children in Africa. Women were more likely than men to have brought children with them to the UK.⁸⁶

Children's views

Very few presentations discussed how children themselves perceive and experience living with HIV. One exception was an ongoing study in Puerto Rico looking at 'emotional indicators mediating children's understanding of their disease'. Ingrid Mendez and colleagues argued that 'The assessment of emotional well-being is a central issue in the case management of the HIV infected child' and called for more research into 'children's capacity to cognitively understand their illness process as well as the therapeutic interventions they are subjected to'.⁸⁷

Ana Maria Baricca described her work as a psychologist working with children with AIDS in Sao Paulo. She has been encouraging children to draw pictures and then talking with the children about them, to help them 'express feeling like fear, anguish, anxiety, anger, etc.' One case illustrated the impact of children dying in a hospital ward on other children.

A child drew a graveyard and said 'The last time I was in the other bed. Now I'm in Sabrina's bed. I liked her... I remember Sabrina and now I'm where she used to be' (Sabrina had recently died).⁸⁸

MODELS OF CARE

Children's needs should be addressed in the context of the family as a whole. In Vancouver, Canada, a Women and Family HIV Centre has been established which 'acknowledges the inter-relatedness and complexity of HIV infection in family units'.⁸⁹ The centre is multidisciplinary outpatient facility designed to address the medical and psychosocial needs of women, children and families in one setting.

There is also a need to develop community-based models of care. In Rome, Italy, a programme of Home Care for children with HIV is being developed involving medical and nursing staff, social workers and psychologists. Early experience has demonstrated that 'it is possible to provide care to pediatric AIDS patients with an integrated model of care (hospitalisation, day-hospital and home assistance); this model can relieve the number and the length of hospitalisations, reducing their costs and improve the quality of life'.⁹⁰

In Porto Alegre, Brazil, a Pilot Transitional Residence is providing social and health services for children with HIV/AIDS (aged up to eight-years-old) in a context which 'seeks to facilitate their integration into stable living conditions'. Hospital stays have been reduced, and children's quality of life improved.⁹¹ A 'supporting house' for 30 orphaned or abandoned children with HIV has been established in Rio de Janeiro in order 'to reduce the unnecessary long-term permanence in hospitals due to social problems'.⁹²

SATELLITE MEETING: 'CHILDREN IN A WORLD WITH AIDS'

A meeting was held in Yokohama of people interested in a proposed international project on the implications of the HIV/AIDS pandemic for the physical, mental and social well-being of children. The project will aim to 'develop and promote a new understanding and approach to the problems of children living in a world with HIV/AIDS' in the context of 'the broader perspective of children's health and children's rights'.⁹³ Proposed activities include information-sharing and a major international conference.

The holistic, multidisciplinary approach envisaged in the 'Children in a World with AIDS' project is broadly in keeping with that developed by the European Forum on HIV/AIDS, Children and Families (and by the National Forum on AIDS and Children in the UK). Unfortunately, with some notable exceptions this approach did not inform the discussions of

children and families in Yokohama, with the structure of the conference tending to encourage fragmentary perspectives in which children's physical, psychological and social needs were treated as separate areas.

CHILDREN, FAMILIES AND HIV: THE NEXT STEPS

The Tenth International Conference on AIDS in Yokohama generated much useful information on children, families and HIV, but some important areas were marginalised and largely neglected. In order to gain a more complete overview of the effects of the epidemic on children and families, and to meet the diverse needs of those affected, further research is required into such areas as:

- The social and psychological impact of HIV and AIDS on children and families, including how the disease is perceived and experienced by children and other family members, and the effects of discrimination against families affected by HIV.
- Children's rights: children are not simply the passive objects of clinical and social interventions, and as they grow older they become progressively more able to play an active role in their own care. Research is required on how to facilitate children's participation and put their rights into practice.
- Support for families: the family is often the main care giver for people living with HIV and AIDS, supported in different parts of the world by various configurations of health, social and education services. Research is needed into how these different services can work effectively together to support families, responding flexibly to the needs of family members as they change over time.
- The implications of population displacement through war, famine and other political and economic problems for children and families affected by HIV: the needs of different groups such as homeless street children or refugees require special attention.

The European Forum on HIV/AIDS, Children and Families is committed to working with other networks to develop an agenda focusing on these and other issues.

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